ELECTRONIC PERSONAL HEALTH RECORDS

EMERGENCE AND IMPLICATIONS FOR THE UK

A report to the Nuffield Trust
by Claudia Pagliari PhD, Don Detmer MD, Peter Singleton MBA

The Nuffield Trust
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SUMMARY

This report is based on an expert workshop on electronic Personal Health Records (ePHR) hosted by the Nuffield Trust (London). The 15 participants, representing senior figures from the areas of clinical medicine, health policy, academia and consumer advocacy, were brought together to share information and exchange views on the emergence and potential of ePHRs and the implications for implementation in the UK context. The event was organised around a series of working papers dealing with concepts, theory, practical experience, research evidence and opinion. Across these domains, participants were encouraged to reflect on the relative advantages of alternative models, barriers and facilitators to adoption (e.g. patient/clinician acceptability, security/confidentiality), potential impact (individual/system/societal levels), limitations of existing evidence/research needs and implications for the NHS. Discussions were facilitated and running notes taken.

Electronic Personal Health Records represent a relatively recent innovation and, although there is still little evidence to illustrate their effectiveness, their use is increasing World Wide. Emerging models of ePHR vary in complexity, interactivity and integration with the wider electronic health record (EHR), as well as the extent to which they are governed by the patient or provider and their accessibility by alternative healthcare professionals. The appropriateness of such models will be determined by individual patient utilities and features of the healthcare system and culture.

Participants expressed an overriding optimism around the potential of ePHRs for supporting patient empowerment and aiding clinical practice. This was thought to be consistent with policies advocating patient choice and self care and the trend towards increasing use of the World Wide Web (WWW) for health information, as well as addressing national and global visions for eHealth.

It was agreed that ePHRs have the potential to improve *communication* between providers and patients by sharing information, to enhance the *quality* of records by highlighting inaccuracies, and to reduce the *burden* of care by engaging patients in managing their own health and illness.

Experiences from limited implementations of ePHR in the United Kingdom, and elsewhere, suggest that patients have, on the whole, responded positively. While some express concerns over security and confidentiality, few problems have been reported and it would appear that potential risks are being traded-off against the utility gains afforded by ePHR (with individual variation). A key factor mediating this relationship is trust which has traditionally been enjoyed by doctors more than other professions and which research suggests is itself enhanced by shared record access.

While fully interactive and integrated ePHRs were considered a desirable goal for the NHS, the technical and economic challenges involved in ensuring secure and reliable data flows between NHS-Net and the WWW were recognised. Greater standards and policies for data sharing and access, and for ensuring interoperability, were perceived as facilitators.

In order for ePHRs to have benefit, they need to be appropriately integrated into the care process and changes in patient-clinician relationships must be anticipated and effectively managed. This is likely to require changes in professional practice and culture. Crucially, the design and introduction of ePHRs needs to be driven by research on users' (clinicians and the public) requirements, attitudes and levels of risk tolerance, as well as evidence on how patients use e-records in practice and their impact on quality, efficiency and safety.

With these caveats, the participants were highly supportive of planned internet records access via NHS HealthSpace and keen to see the development and implementation of this service.

BACKGROUND

The emergence of electronic health records (EHR), along with an increasing emphasis on patient-centred approaches to care delivery, a growing culture of consumer empowerment, and widespread computer literacy, are generating a need for patients to have access to their own electronic health data. The evolving concept of the electronic Personal Health Record (ePHR) relates to models of achieving this. At its simplest this involves giving patients access to portions of their provider-held electronic record, either in the clinical setting (e.g. consulting room or waiting room kiosk), via patient-held devices (e.g. CD), or using the Internet. However the functionality of ePHRs is evolving rapidly and they are becoming increasingly multifaceted, interactive and tailored in order to support personal health administration, education, clinical communication, and chronic disease self-management. The Internet (including web-linked mobile 'phone) is set to become the medium of choice in the near future, potentially allowing access anywhere, any time.[1, 2]

The strengths and drawbacks of different models of ePHR are still being explored, but their potential benefits include increased patient empowerment for health, therapeutic adherence and continuous/shared care, along with concomitant improvements in clinical outcomes. They have also been advocated as a means of eliminating geographic barriers to healthcare; an issue which has become prominent with the occurrence of major natural disasters and the increasing risk of bioterrorism. Importantly, in healthcare systems where individual patient care may be provided by multiple organisations, they have potential as a point of integration for disaggregated health records.[3, 4]

Nevertheless the area has generated debates around who 'owns' patients' data, who should get access, how to maintain confidentiality and ensure data validity, who should pay for ePHR development and maintenance, and their potential impacts on the patient-professional relationship and the quality, safety and cost of healthcare.

While research to inform these debates is increasing, the evidence-base lags behind the growth in development and adoption of such systems.

This expert workshop was held in order to explore these issues and their implications for the development of ePHRs in the United Kingdom. It was prompted by three main factors:

a) a scoping study on international approaches to ePHR by DD and Elaine Steen[5]

b) plans for patient EHR access within the National Health Service (NHS) Programme for IT and

c) the organisers' research interests in EHR and patient involvement.

As part of an overall plan to create integrated care records within the NHS, all UK citizens are to be offered internet access to a summary of their primary care EHR by the end of the decade. In England this will occur via an internet portal known as NHS HealthSpace, which offers patients the option to create personal health notes, view and book appointments and access health information, amongst other features[6]. Despite localised experiences of electronic record access, at the time of this workshop there had been little explicit discussion of the ePHR concept within the UK and HealthSpace was at an early stage of maturity, offering an opportunity to influence the agenda.

Workshop aims

- To explore the concept of the ePHR and alternative emerging models.
- To consider international experiences of ePHR adoption, with particular emphasis on examples from the United Kingdom.
- To consider the potential of ePHRs for improving the quality and safety of patient care and the patient experience, as well as challenges and drivers to implementation.
- To consider the implications for NHS policy and practice, including HealthSpace.
- To identify needs for further research.

Discussions were focused around a series of short working papers, drawing on concepts, evidence, theory and practical experience, as detailed below:

● ePHR concept and potential	Dr. Claudia Pagliari
● International experiences	Prof. Don Detmer
● ePHR activities/plans in the UK:	
○ The PAERS project	Dr. Brian Fisher
○ NHS England CfH (HealthSpace)	Dr. Mike Pringle
○ NHS Wales Informing Healthcare	Dr. Martin Murphy
○ NHS Scotland eHealth strategy	Dr. Claudia Pagliari

Discussions were actively facilitated by DD and participants were encouraged to reflect on the issues reflected in the aforementioned workshop aims.

Participants

Participants were selected to represent a range of clinical, policy and academic perspectives, including consumer engagement, in order to promote the exchange of experiences and opinions across stakeholder groups. In many cases, individual participants represented two or more of these domains and one participant had extensive experience of giving patients access to their records in clinical practice. Importantly, the group contained high level representation from the national programmes for Information Technology in England (NHSConnecting for Health), Wales (NHS Wales Informing Healthcare) and Scotland (NHSS eHealth Programme). A total of fifteen people participated.

Table 1. Participants & Representation *(listed alphabetically)*

Name	**Job title & Organisation**	**Role & Background**
Nessa Barry	Researcher, NHS Education for Scotland, representing Scottish Executive Health Department.	Nominated by SEHD eHealth Strategy Lead. Involved in research & implementation activities around eHealth, particularly telemedicine.
Dr Gillian Braunold	Joint Primary Care Clinical Lead, NHSConnecting for Health; General Practitioner, Kilburn Park Medical Centre, London	Strategic role in clinical engagement for NHS CfH. Includes the NHS Care Records Service from which the Summary Care Record is destined to be adapted for patient access via NHS HealthSpace.
Professor Don Detmer	President & CEO, American Medical Informatics Association & Professor of Medical Education, University of Virginia Fellow of the Nuffield Trust.	Former surgeon and international expert in health policy, healthcare administration and medical informatics. Major contributor to national healthcare IT strategies in the US and worldwide. Involved in extensive analysis of ePHR developments internationally.
Dr Brian Fisher	General Practitioner, Wells Park Surgery, London. Involved in patient and public involvement activities for NPfIT.	Has successfully used electronic access in primary care via waiting-room kiosks. The technology is to be launched commercially and an internet portal is being trialled. Has also conducted related research around patient attitudes and desires for access. Recently engaged as an advisor to NHS Connecting for Health.
Dr Nick Gaunt	Specialist Associate, Technology and Product Innovation, NHS Institute for Innovation and Improvement	NHS policy analyst and researcher. Previously involved in evaluating patient access to e-records via the NHS ERDIP Programme. Has authored a number of scoping and policy reports for the NPfIT Care Record Development Board, around legal, ethical and governance issues surrounding record integration.
Dr Dipak Kalra	Clinical Senior Lecturer, Centre for Health Informatics and Multiprofessional Education, University College London	Academic general practitioner involved in research on electronic health records and security issues.
Professor Bill Maton-Howarth	Chief Research Officer for Public Health, Department of Health	Key strategic role in NHS policy and R&D commissioning. Interests in electronic health records and patient/public issues.
Liz MacDonald	Policy Manager, Health and Social Care. Scottish Consumer Council	Engaged in research on consumer attitudes around electronic health records. Interface between policymakers and public.

Name	**Job title & Organisation**	**Role & Background**
Dr Martin Murphy	Clinical Director of Health Information and Knowledge, Informing Healthcare Programme, NHS Wales	Key strategic role within Welsh national programme, with particular remit around the development and implementation of the Individual Patient Record and Emergency Health Record.
Dr Claudia Pagliari	Senior Lecturer in Primary Care & Chair eHealth Research Group, University of Edinburgh	Expert in health technology assessment, medical informatics and patient involvement. Experience of evaluating national and regional health information technology programmes (including functional and sociodynamic aspects of integrated diabetes care records). Involved in ePHR developments in diabetes.
Dr John Powell	Senior Clinical Lecturer in Epidemiology & Public Health	Academic public health physician and researcher with a particular interest in eHealth and health information seeking behaviour using the internet.
Professor Mike Pringle	Joint Clinical Lead for General Practitioners. Also Professor of academic general practice, University of Nottingham.	Strategic role in clinical engagement for NHS CfH. Includes the NHS Care Records Service from which the Summary Care Record is destined to be adapted for patient access via NHS HealthSpace. Also engaged in academic research and clinical practice.
Olivia Roberts	Policy Manager, The Nuffield Trust	Attending for the Nuffield Trust
Dr Peter Singleton	Senior Associate & Healthcare Consultant, Judge Business School, University of Cambridge. Director Cambridge Health Informatics Ltd.	MBA with special interest in electronic health records, issues for adoption and workflow integration and patient involvement. Involved in the NHS ERDIP evaluation and Informed Patient projects.
Marlene Winfield	Head of Public Engagement, NHS Connecting for Health	Pivotal role in public and patient engagement for the UK National Programme for IT.

ePHR CONCEPTS, DEFINITIONS & MODELS

Defining ePHR

The concept of the Electronic Personal Health Record (ePHR) has emerged relatively recently, and reflects digital implementations of the broader and older construct of the patient-held record, often referred to as the Personal Health Record (PHR). Numerous definitions of these linked concepts exist and the examples shown below reflect the boundaries applying to alternative approaches, as well as the origins of the ePHR concept within the US.

PHR (may be paper-based or electronic): "a collection of important information about your health or the health of someone you are caring for, such as a parent or child, that you actively maintain and update. The information comes from your healthcare provider, and from you."[7]

ePHR: "An **electronic** application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure and confidential environment" [8, 1]

OR

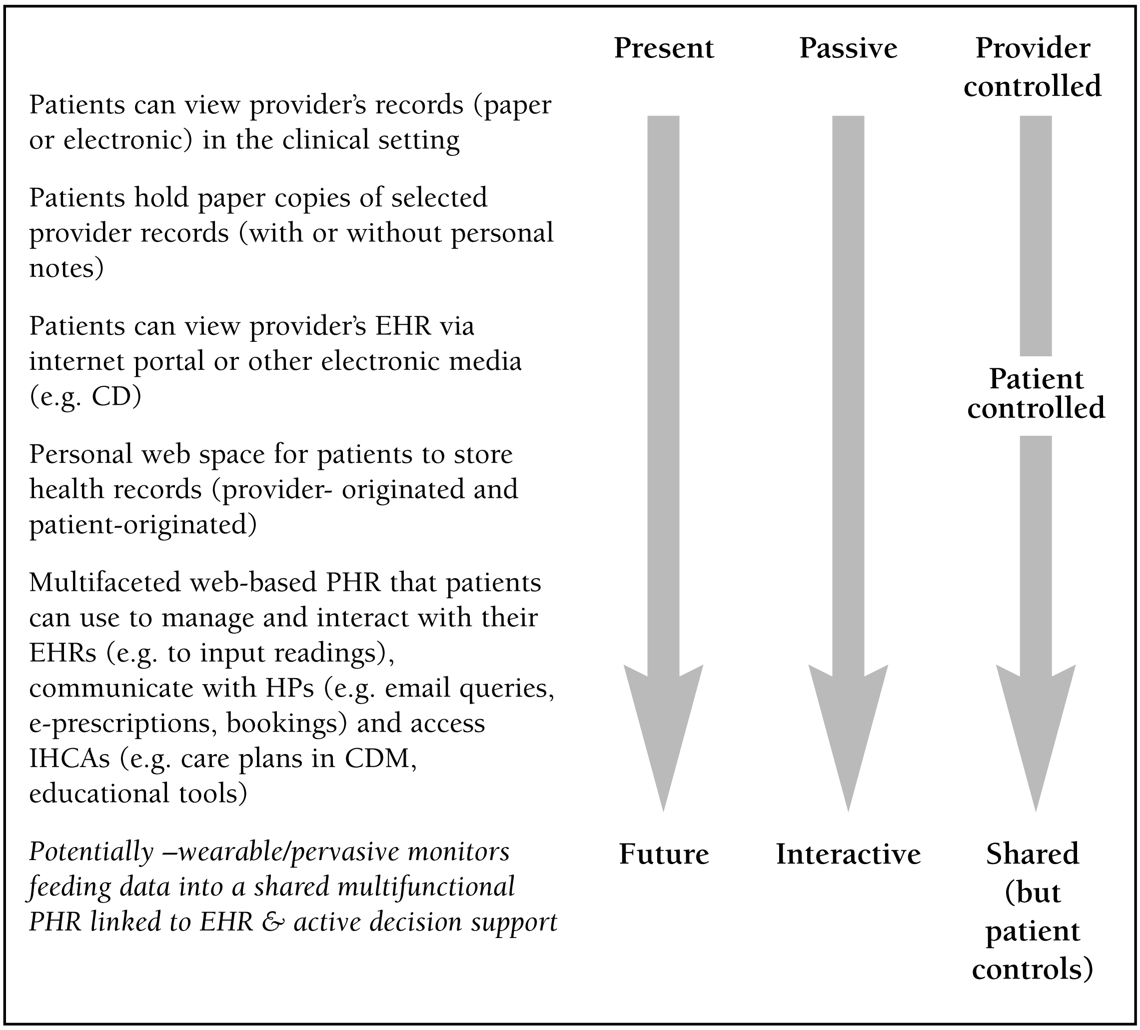
"An **Internet-based** set of tools that allows people to access and coordinate their lifelong health information and make available appropriate parts of it to those who need it"[1]

The term **Electronic Integrated Personal Health Record** (eiPHR) has been suggested to differentiate ePHRs that are integrated with the information technology systems of caregivers from stand-alone records which may receive portions of the provider EHR and/or provide a private space for the individual to record their own health and lifestyle issues[5]. The term '**Personal Health Record System**' has also been advocated to differentiate ePHR that provide static records, from those that encompass software tools supporting patient participation[9]. However for most purposes, including that of the current exercise, the broader concept of the ePHR is sufficient.

Different approaches to and functions of ePHR

The evolution of the PHR can be viewed along many dimensions, including the move from provider-dominated to patient-dominated (and shared) record access and passive to interactive functionality, as well as reflecting the general move from paper to electronic and web media. Figure 1 was presented as a framework for discussion at the meeting. It was emphasised that there is flexibility between the categories and dimensions suggested. For example, within NHS HealthSpace personal diaries are being enabled before the option to view the provider's summary EHR, and increasing digitality does not necessarily represent greater interactivity.

Figure 1. PHR models & evolution



Patients can view provider's records (paper or electronic) in the clinical setting

Patients hold paper copies of selected provider records (with or without personal notes)

Patients can view provider's EHR via internet portal or other electronic media (e.g. CD)

Personal web space for patients to store health records (provider- originated and patient-originated)

Multifaceted web-based PHR that patients can use to manage and interact with their EHRs (e.g. to input readings), communicate with HPs (e.g. email queries, e-prescriptions, bookings) and access IHCAs (e.g. care plans in CDM, educational tools)

Potentially –wearable/pervasive monitors feeding data into a shared multifunctional PHR linked to EHR & active decision support

[From Claudia Pagliari's presentation]

More specific functions offered by ePHRs outlined at the meeting are shown in Box 1.

Box 1. Specific functions potentially offered by an ePHR

- **Access to Electronic Medical Record**
  - Summary
  - Full record
- **Personal record keeping/diary** (access only by patient or those they have permitted) e.g.
  - details of clinics, physicians, tests, dates, non-prescribed treatments
- **Personal health administration** e.g.
  - Appointment scheduling
  - Prescription refills
- **Links to education e.g. about illness, treatments or self-care**
  - Passive information
  - Interactive educational tools
- **Links to other sources of support** e.g.
  - Patient organisations or peer networks
- **Capture of symptom or health behavior data**
  - Subjective self-report
  - Objective monitoring via electronic devices (e.g. fixed/ mobile/wearable)
- **Self-management support** e.g.
  - Passive biofeedback
  - Tailored instructive or motivational feedback, or reminders (decision support)
- **Communication** e.g.
  - Secure clinical email

[Adapted from Pagliari & Detmer's presentations]

Figure 1 was discussed with reference to the actors involved at various levels of ePHR functionality, and the implications for integrated data sources. It was suggested that it may be viewed from the perspective of 'supply-chains' involving, for example, patient-only; patient-GP, patient-GP-hospital, or an integrated supply chain including all stakeholders (patient, GP, hospital, pharmacy, social care, etc). Another prominent theme was patients' rights, including issues of ownership. While the concept of ownership was thought, by some participants, to be unhelpful it was acknowledged that different types of ePHR would confer greater or lesser rights for access, privacy and control and there may be trade-offs to be made in return for additional functionality. This creates an imperative for appropriate standards to ensure transparency of contributorship and access, as well as interoperability and valid data integration. It was also agreed that further work needs to be done to ensure effective management of the dual needs for interactivity between patient and provider-held records, including information 'push' (into the ePHR) and 'pull' (from the ePHR) and the balance of live to historical data. A table elaborating these themes can be found in

Appendix 1. The term **Internet Mediated Integrated Care** was suggested by Don Detmer to describe ePHRs meeting most or all of the criteria in Box 1 within a fully integrated web-based environment.

The ideal attributes of an ePHR outlined by the Markle Foundation were used to stimulate further discussion[1].

Box 2. Ideal attributes of an ePHR suggested by Markle (2004)

1. Access controlled by patient
2. Lifelong records
3. Contains information from all care providers
4. Accessible any place, any time
5. Private & secure
6. Transparent (clear who has added, altered, viewed or transmitted what information)
7. Permit easy exchange of information among health providers/organisations

[Used in Pagliari's presentation]

The participants acknowledged the validity and importance of these characteristics. There was a perception that current plans and policies would facilitate the delivery of points 1-6 in the future of NHS HealthSpace, once technical and public perception issues have been sufficiently addressed, although these potential barriers should not be underestimated. The objective of enabling easy exchange of information among health care organisations (point 7) was thought to be less of an issue in the UK context, where most healthcare is provided by a the NHS and plans for integrated EHR are already afoot, although an intermediate ePHR held outside the NHS EHR would offer an opportunity for third party health providers to contribute. While elective patient-provider information exchange was regarded as appropriate and something to be supported by ePHR the feasibility of integrating patient-generated data to the core EHR was questioned, given the security issues around NHSNet and its interface with the Web, although the potential for solutions to be found (at a cost) was recognised. The role of commercial providers in filling this gap for patients desiring additional functionality was considered, with the caveat that these should be compatible with existing NHS EHR.

EXAMPLES OF ePHR ACROSS THE GLOBE

In order to ground the discussion with reference to real experience, selected examples of ePHR were drawn from the global scan undertaken by the American Medical Informatics Association for the American Association of Retired Persons[5], along with presentations by the workshop speakers. This was not intended as an exhaustive list of ePHR, but merely as a means of illustrating their variety and implementation in a range of settings. Given the context of the workshop, particular attention was paid to experiences and plans in the UK. Subjective experiences and results of evaluations were referred to in a subset of cases. Summaries are reproduced in Box 3, which is based on Don Detmer's presentation, with elaboration on UK examples from presentations by Brian Fisher, Mike Pringle, Martin Murphy and Claudia Pagliari. Links and references are provided for further reading (updates are included in some cases).

Box 3. Examples of UK and international ePHR discussed at the meeting

USA

- ePHR are rising on the policy agenda, supported by legal efforts to enable patients to see their health records and the role of patient empowerment in the quality debate. Early online PHRs focused on patient-only data with no integration to provider, but these failed to deliver significant value. ePHRs have since become increasingly complex and interactive, for example, incorporating electronic communications and education in addition to records access. Employers and insurers are pushing for EMR systems to reduce costs and improve care.
- A number of organisations have developed secure online ePHR based on the MyChart® software produced by Epic Systems (http://www.epicsystems.com/Software/eHealth.php#MyChart). The Cleveland Clinic offers online portal where patients can review past appointments and records, manage prescription renewals, appointment requests and cancellations, and access reliable health information (https://mychart.clevelandclinic.org/). PAMFOnline provides patients of the Palo Alto Medical Foundation with access to their health records and test results, along with patient-clinician email and appointment requests (www.pamfonline.org).

Kaiser Permanente's "Your Health Record" is available to over a million patients, offering records of allergies, immunizations, future appointments, diagnoses, instructions from past visits, as well as lab results, prescription refills, appointments and patient-provider email. Parents can access the records of their children. In 2006, over 800,000 patients had used the facility, and had viewed almost 4 million lab results online and sent over 1.4 million email messages to their providers, mostly to physicians (www.kp.org).

- ○ Beth Israel Deaconess Medical Center operates PatientSite (www.patientsite.org), produced by CareGroup Healthcare System (www.caregroup.org), which offers access to personal health records, clinical email, health administration (prescriptions, appointments, referrals, billing) and links to health information and education.
- ○ The US Veterans Administration is developing ePHR, via its My Health eVet gateway, including a personal and family health record, health status graphing, health summary reports, and a prescription renewals facility. (http://www.myhealth.va.gov/)
- ○ iHealthRecord is an online personal health record developed by Medem Inc. in partnership with leading medical societies, patient advocacy groups and government agencies. It is available at no cost to physicians registered with the Medem network and their patients. (http://www.medem.com/am/am.cfm). The Connecticut iHealthRecord Adherence Service Clinical Trial tested the impact of adherence messages on use of Statins & Antidepressants, initially in 100 Study Group vs Control patients. At 6 months 2/3 believed that the Adherence messages from their doctor helped them better understand their medication & manage their condition, 95% found the Adherence Service easy to use & agreed that it "could be an important part of helping busy doctors provide extra care and information to patients." Medication drop-off reduced by over 40%. This study has since continued and iHealthRecord is now being rolled out to thousands of patients (www.ihealthrecord.org)

Canada

- ○ The focus has been on developing architectures to foster secure, private and interoperable EHR. At the time of the workshop there had been only limited work on ePHRs; however the concept was acknowledged as a long term goal for the Canada HealthInfoway. (http://www.infoway-inforoute.ca/en/WhoWeAre/Overview.aspx)
- ○ An ePHR is being developed for diabetes management in New Brunswick (National Research Council Institute for Information Technology)

Australia

- ○ DoctorGlobal (http://info.doctorglobal.com/) is a private health care organisation offering patients access to their electronic health record, patient-provider email and risk assessment tools via its Mylife health record.
- ○ HealthConnect is a national quality improvement programme which has, as one of its key objectives, the development of integrated health records. As part of this there are plans to give patients access to and the ability to contribute to their personal electronic health record in the future. (http://www.health.gov.au/internet/hconnect/publishing.nsf/Content/intro)

New Zealand

- ePHRs are not part of the current national strategy but the focus on the National Health Index (UPI), privacy framework and chronic disease management, provide a strong foundation

Sweden

- SUSTAINS (Supports Users To Access Information & Services) provides users with access to their own medical records through the Internet in Uppsala, Sweden. One-time passwords are distributed through cell phones, giving access to data from hospital information system, laboratory database, & GP medical records. Evaluation revealed that a less complex technical environment is better for users; patients were most interested in seeing their medical records, booking visits, communicating with health care providers, viewing prescription lists, & reading fees; most users were not concerned about security risks and the process appeared to increase confidence & trust in physicians. (http://unpan1.un.org/intradoc/groups/public/documents/UNPAN/UNPAN023597.pdf)

United Kingdom

- Patients in the United Kingdom have had the legal right to access their medical records for several years, although few have taken this opportunity. This may be attributable to the inconvenience or embarrassment of requesting and viewing personal records in the clinical setting and the costs of obtaining portable copies. National health information strategies encompass plans to enable patient access to summary EHR via the internet, although the timescale and nature of this varies between parts of the UK (see below).

England

- NHS HealthSpace is a secure online personal health organiser developed under the auspices of NHS Connecting for Health. At the time of the workshop, HealthSpace had recently begun to offer patients the facility to develop personal medical diaries and view appointments and sources of health information. (Incorporating Choose & Book, Calendar & Reminders, Health Details and eLibrary). Functionality has since been extended to include personal recording and graphing of chronic disease indicators such as blood sugar, peak flow and cholesterol, and a glossary of drugs and medicines. From 2007 patients registered with HealthSpace will be able to access their Summary Care Record via the National Care Records Service and in future may be able to edit certain fields (e.g. change of address) or contribute information about how they wish to be treated and their access needs This initiative supports other moves towards patient choice in the development of NHS integrated care records, such as the opportunity for patients to opt out or to have access to parts of their EHR restricted to specific health professionals (referred to as the ‘sealed envelope’ system). (https://www.healthspace.nhs.uk/)
- The PAERS system, developed independently by Dr Brian Fisher (Wells Park Practice, London) and colleagues, has been successfully piloted in primary care and, at the time of the workshop, was entering a commercial phase of development in collaboration with GP system supplier EMIS. Patients access their general practice record using secure waiting room kiosks, with identify verification by fingerprint

recognition. Screen tips and glossaries of clinical terms are used to improve understanding. Evaluation of the service suggests that most patients take advantage of the opportunity to view their records and find this useful, although few access it regularly. While a small number of patients were upset by what they read (usually those with psychiatric problems), all felt that the process was right, encouraged confidence and improved patient-doctor communication. A number of errors in the record were identified by patients, although not all informed the practice. While clinicians were initially wary about patient acceptability and risks, the experienced reality was benign and routine – it helped patients but did not produce dramatic changes and concerns about litigation were unfounded. Patients are more concerned about the accuracy of records and the recording of fingerprints than the dangers of unauthorised access. At the same time it highlighted the need for clinicians to be judicious in their use of language, mindful that the records would be read by patients. This experience suggests that PAERS offers an effective and pragmatic method of delivering ePHR, is associated with few problems and can help to change practice and improve the quality of records. Implications for practice are that clinicians need to be more open with patients and less paternalistic. An online version of PAERS has recently been developed and a pilot, involving 100 practices, was announced in February 2007. (http://www.paers.net/).

- GP Dr Richard Fitton, of Hadfield Medical Centre, Derbyshire, has been providing patients with copies of their electronic records for several years, via print-out, CD-Rom and USB, as well as offering some the opportunity to send blood pressure and blood sugar readings via secure email. Since the workshop the practice has begun providing online records access via PAERS.
- Commercial companies are increasingly playing a role in the UK. At the time of the workshop PEMMS International, based in Ascot, was marketing a patient managed, ePHR accessible online, using a smartcard with a unique identification number. Company operations have since moved to the USA (http://www.pemms.org/)

Wales

- A key objective of the Welsh national programme, known as Informing Healthcare, is to deliver an Individual Health Record (equivalent to an integrated EHR). While there is no plan, as yet, to offer all patients access to a summary care record, ePHR are being developed for chronic disease management. MyHealthOnline –builds on existing patient-held maternity paper records rather than introducing new untried approach. It stores information on identity and preferences, carers (formal and informal), summary medical information and information on events and communications; and there is authentication for patients and clinicians. The emphasis is on communication and co-ordination of care. (http://www.wales.nhs.uk/ihc/documents/IHC_National_Case.pdf)

Scotland

- As part of its National eHealth Programme, Scotland is introducing a single electronic health record that will utilise the Unique Patient Identifier to facilitate records integration across care sectors and thus the ePHR. At the time of the workshop there were no specific plans to develop an ePHR along the lines of

NHSHealthSpace, although the possibility of giving patients access to key information in their general practice record had been discussed as part as the planned rollout of the Emergency Care Summary Record. This is a snapshot of the GP record offering access to key medication, allergy and demographic information by Out-of-Hours medical practitioners. The ECS is now being rolled out for Out-of-Hours GPs and emergency care and the government is committed to offering patient access in the near future. Qualitative research conducted by the Scottish Consumer Council has explored a number of issues around public attitudes to health data sharing and the ECRS and there is general support for the idea among most consumer groups. (http://www.ehealth.scot.nhs.uk/

- ○ The Babylink system used in neonatal intensive care in Edinburgh gives parents access to their child's records via the web, supported with a hyperlinked glossary in lay terms. It also allows parents to view static images of their child on a daily basis. These are linked to diaries written with the baby as first person, to help build relationships and prepare parents for poor outcomes. Evaluations indicate that the system has had high patient acceptability and utility. (http://www.babylink.info/Edinburgh/BabyLink/Intro_page.aspx)
- ○ RenalPatientView, is a secure web-based portal developed within the nephrology service in Lothian, which allows patients to access their health records via the internet. Records are currently displayed in the form the clinician sees, but there are plans to tailor this to patients. There are also links to information about kidney disease/treatments and services. Since the workshop the system has been rolled out in a number of hospitals across Scotland and England (www.renalpatientview.org)
- ○ Email pilots in primary care (Westgate Health Centre, Dundee) offer insights into some aspects of ePHR. Patients were willing to communicate with GPs for consulting, booking & prescription renewal requests, using non-secure email and reported positive attitudes and experiences. The use of SMS for delivering aspects of this service and records access, is currently being explored.

[Links are for product or project web pages. Evaluations referred to in some cases are referenced in Box 5. All sites were last accessed on 28.02.07]

Discussion of these examples focused on the role of healthcare economy, service organisation and culture on the possible effectiveness of different approaches. For example, the US focus on organisation-centred health care services and lack of state support for ePHRs make widespread implementation difficult. This is compounded by the lack of a universal patient identifier (UPI), which acts as a barrier to record integration in countries such as the US, in contrast to the UK and other parts of Europe. Greater use of UPI and standards for ensuring systems interoperability were advocated in this regard. Baseline service arrangements and customer expectations are also likely to have an influence on the ease with which systems are adopted. For example, in France patient held records (paper-based) are already the norm, while Minitel and its internet successor have fostered a culture of patient involvement and control. The contingencies and incentives operating on different care sectors are also important – For example successful ePHR adoption may be highly dependent on organisational change in one professional group (e.g. primary care), but may provide few benefits for them in the short term.

POTENTIAL IMPACT OF EPHR

The potential impact of ePHR on patients and health care providers was considered with reference to hypothetical benefits, existing research results and lessons learned from early adopters.

Hypothetical benefits

Box 4. Summary of Potential ePHR Benefits

\+ Patient empowerment (i.e. participation, control, education)
  - Better self-management & medication concordance
  - Increased participation in treatment decision making
  - Greater knowledge

\+ Health gains
  - Better health/quality of life, reduced illness

\+ Quality of care
  - Improved relationships with health professionals
  - More flexible access to services (e.g. appointments, lab results, electronic consulting)
  - Increased patient safety (e.g. fewer recording errors, better access to risk information)
  - Reduced provider liability (assuming improved self-management & health)
  - Ability to track patients' 'hidden' health behaviours and medications

\- Burden of care
  - Fewer unnecessary consultations, reduced waiting lists
  - Lower costs (due to better health and reduced use of services and treatments)
  - Reduced provider liability (if increased patient control improves self-management)

[Adapted from Pagliari's slides]

Potential benefits were also considered with reference to alternative models of ePHR. To avoid duplication these are summarised in Appendix 2.

Research evidence on ePHR

Research on patient access to paper-based health records has indicated a number of benefits that are also likely to generalise to ePHRs, while at the same time overcoming legibility problems. These include improved doctor-patient communication, adherence, patient education, and empowerment (Ross & Lin, 2003). However evidence pertaining specifically to accessible EHR, and more complex models of ePHR, remains limited (Protti & Eggert, 2005, Tang et al, 2006). Key messages from the research literature were highlighted in presentations by Brian Fisher, Don Detmer and Claudia Pagliari and these have been converged, elaborated and referenced in Box 5.

Box 5. Evidence on ePHR (includes primary and secondary sources)

- Improves relationships with clinicians by creating transparency, promoting informed discussions and engendering trust and a sense of involvement [10, 11]
- Increases confidence in self-care and control [10, 12, 13, 14, 15]
- Can reduce errors by validating against patient recall and knowledge [11, 16, 17]
- Some patients have concerns about security and confidentiality (more in the case of patients with psychiatric conditions) although these do not appear to have acted as a barrier to use in trials of ePHR. [10, 16, 18, 19, 20, 21]
- Improves compliance in heart disease, hyperlipidemia and depression [22, 23]
- Perceived as acceptable and useful by most patients, particularly people with long-term conditions. In complex ePHR, patients particularly value secure messaging, online refills, lab results, & disease management plans in addition to charts and medication lists. [10, 16, 22, 24, 25, 26, 27]
- Clinicians' fear access will create misunderstanding and expose weaknesses in care, but these appear to be unfounded. Physicians generally more concerned about security risks and patient safety than patients. [12, 16, 28, 17]
- Little evidence is available relating to the risk of confidentiality and privacy violations, nor of the effects of records access on patient litigiousness.
- No evidence of adverse impact on workload or safety [12, 27, 28]
- Simply providing access to electronic medical records is unlikely to confer clinical and efficiency benefits. Multifaceted and interactive tools directed at promoting self-care and communication are likely to be necessary. [1, 14]
- Most studies have looked at patient and clinician attitudes and satisfaction. Only a small number have examined actual experiences of ePHR usage by patients. Few studies have looked at clinical and safety outcomes. [12, 24, 29]
- The impact of patient accessible records will depend on social/contextual factors affecting implementation (e.g. culture of collaborative care) and further studies are needed to examine these.[31]

[Based on presentations by Don Detmer, Brian Fisher and Claudia Pagliari. References represent key sources of evidence illustrating each point and the list is not intended to be exhaustive.]

Lessons from early adopters

To supplement the published literature, Don Detmer reported lessons learned from early adopters, based on the case studies for AARP.

Box 6. Lessons from Early Adopters in the US

Clinicians

- Physician promotion is key to getting high consumer adoption in most places.
- Physician acceptance requires large up-front efforts to gain buy-in.
- If ePHR is viewed as beneficial only to patients, it's hard to get physician support.
- ePHR is not likely to be incorporated into clinical workflow without addressing EHR integration.

Patients

- Patient-provider secure messaging, online refills, lab results, medication lists, & disease management plans are particularly useful.
- Patient-provider messaging wins over an enthusiastic subset of both patients & doctors, & does not overwhelm the inbox of doctors.
- Patients feel more empowered when they have access to their office chart information, & many early physician adopters find that helpful.
- People with chronic conditions are most likely to need & use EPHR-type applications.

Organisational needs

- National patient identifiers or defined approach to authentication
- Strong infrastructure (e.g., standards, privacy framework & technical support)
- Sound funding strategy
- Buy-in by health care professionals

[From Don Detmer's presentation]

CHALLENGES AND FACILITATORS FOR EPHR

Participants discussed a range of challenges and unanswered questions for ePHR implementation, drawing on the aforementioned research and experiential learning, as well as broader considerations around the diffusion of healthcare innovations and the current NHS technology and policy environment. These are summarised in Box 7.

Box 7. Challenges for ePHR implementation

- Managing change
  - Organisation of care:
    - Integrating ePHR into care delivery processes. May require changes to workflow organisation (or gatekeepers) and new responsibilities
    - Developing guidance for best practice
    - Agreeing incentives & reimbursement mechanisms
    - Managing potential risks of transferring responsibilities to patients
  - Culture:
    - Clinicians: Encouraging customer-centred models; tackling fears over confidentiality, power and litigation; managing new responsibilities
    - Patients: Encouraging participative & shared interactions (may require pubic awareness raising & education)
    - Relationships: Managing changes in balance of power/knowledge, developing trust
- Preserving privacy & confidentiality
  - Authentication & Security:
    - Effective patient identification
    - Permitting parental access
    - Risk of Confidentiality breach
    - ‘Ownership’ of record/conflicting rights (managing individual and shared rights)
    - Patients may not be well-placed to assess/manage risk of online access

- Accuracy/relevance/interpretation of data
  - Relevance/completeness of existing record (if created for specific purpose).
  - Data entered for one purpose may not be appropriate for another
  - Accuracy of patient-entered data (room for greater subjectivity)
  - Ensuring sufficient supporting information to enable appropriate patient interpretation (potential for medical terminology to confuse or worry patients)
- Establishing impact and understanding context
  - The nature and direction of impact on processes, outcomes and costs needs to be more firmly established. (For example, could lead to shorter visits if patients are more informed, compliant and healthy, or longer visits if empowerment creates new discussions; benefits of chronic disease self monitoring may be predicated on greater clinician support.)
  - Interpretation of impact and acceptability studies must be informed by qualitative examination of contextual factors (social, organizational, economic, cultural). Using critically rooted methods such as action research to inform ePHR development and implementation activities will help to maximise their impact.
- Funding model/cost-justification
  - Business models are unproven:
    - What are the likely economic and other benefits for providers and consumers? Are there any negative financial effects (e.g. for the NHS, increased demand for remote services or, for insurers, decreased premiums)?
    - What investment will be required to set up and maintain effective ePHR and who will bear the cost? How will providers be reimbursed for new services?
    - What is the consumer demand for these services in the UK (potential for adoption only by ‘worried well’ or similar segments of the health market)?
- Accessibility & usability
  - The ‘digital divide’ may produce inequalities in access, hence other modes such as kiosks, mobile phones and Digital TV may be valuable alternatives. Commercial applications may offer additional functionality to those that desire it, but at the risk of further inequalities.
  - To be successful ePHR need to be intuitive and easy to use, and this will be facilitated by participative development and evaluation
- Standards
  - Essential for ensuring interoperability of databases & systems

[Synthesis of workshop presentations and discussions]

There was broad agreement that the adoption of ePHR in the UK (including NHSHealthSpace) is likely to be facilitated by the factors described in Box 8.

Box 8. Facilitators to the adoption of ePHR

- Further evidence of the acceptability of ePHRs to members of the UK public
- Persuasive evidence of the potential impact of ePHRs on clinical processes, outcomes and softer quality measures (e.g. perceived empowerment, patient-centredness of care)
- Efforts to integrate ePHR into care processes, which may involve reorganisation of service pathways and changes to traditional delivery mechanisms (e.g. from direct to indirect).
- Engagement of clinicians (and support personnel) in the process of developing and implementing ePHR, to promote a sense of ownership and value, as well as training in technical and socio-ethical issues around use.
- Cultural change moving clinicians and patients towards more consumer-centric models promoting shared information and decision making.
- Public awareness-raising activities around rights & availability of access as well as targeted educational interventions
- Adoption of standards and policies for secure and reliable data transmission and access control, as well as database and systems interoperability. Includes implementation of Universal Patient Identifier to enable valid record linkage.
- Guidance on best practice, expectations and reimbursement procedures for healthcare providers
- Creating access to ePHR using flexible methods to overcome digital inequalities (e.g. kiosks, Digital TV)
- Clarity and consensus on funding and reimbursement mechanisms

[Synthesis of workshop presentations and discussions]

DISCUSSION: IMPLICATIONS FOR THE UK

Within the UK, as elsewhere, there has been a close association between the health technology and patient information policy agendas (Box 9). On the technology side, information is seen as the key to supporting evidence-based clinical practice, the efficient organisation and delivery of services and the quality and safety of healthcare. On the consumer side there has been a growing emphasis on informing citizens and patients about lifestyles, illnesses and treatments with a view to harnessing their motivation and ability to self-care. This is linked to the patient choice agenda, which is predicated on greater access to information about the organisation of care and the performance of healthcare providers. The association has become stronger with the increasing use and integration of electronic health records and ePHR offer new opportunities to bridge these agendas.

Box 9. Convergence of Patient Information and Health Technology Agendas

"Without information there is no choice…. The future is about sharing information, sharing decisions and sharing responsibility" (précis) Better Information, Better choices, Better Health: Putting information at the centre of health. UK DoH Dec 16th, 2004 [31]

"Many envision a health care industry that is consumer-centric and information-rich, in which medical information follows the consumer, and information tools guide medical decisions…This will result in fewer medical errors, fewer unnecessary treatments or wasteful care, and fewer variations in care, and will ultimately improve [patient] care." Delivering Consumer-Centric and Information-Rich Health Care, US Department of Health and Human Services, July 2004 [32]

In the UK, experience with electronic record access and associated ePHR functionality has largely been confined to a small number of enthusiastic primary and secondary care groups. Although the lessons learned have been valuable and echo those of larger implementations in the US, the feasibility and benefits of widespread ePHR have yet to be demonstrated. Internationally, there is a lack of hard evidence illustrating the benefits of ePHR for quality, efficiency and patient outcomes, although formative research suggests improved perceptions of patient-centred care, empowerment for health self-management and the potential for improved data quality and medication compliance. It also suggests that while anxieties around confidentiality, impact on workload and potential for litigation may act as barriers to adoption in the early stages, these will dissipate as experience grows. Most patients will welcome access to ePHRs, but few will consult them regularly. The most frequent users are likely to be patients with long term conditions (or their carers), who have the greatest need to track their illness and treatments and manage interactions with the health service, and those experiencing episodic periods of care that generate new information needs. For example, the use of ePHR in patients with diabetes and those undergoing IVF treatment has recently been described[33, 34]. The implementation of record access and associated functionality within NHSHealthSpace offers an opportunity to test these assumptions in large samples of the population.

Necessary protection of data integrity and security will limit the entering of patient data into the core EHR from outside the NHS and HealthSpace is most likely to be useful as an intermediate repository into which provider records may be imported and personal records written, along with additional administrative and informational functions. In the future, the merging of HealthSpace with related patient facilities such as NHSDirect Online may offer new opportunities for electronic consulting and decision support, along the lines of some US ePHR systems. The increasing availability and use of digital health monitoring devices may create a new source of data to be integrated within the ePHR, although experts have cautioned that this will not yield benefits unless clinicians are available to interpret and respond to this information, and this may raise new issues for workload, responsibility and liability[1]. It is likely that more advanced models of interactive ePHR will be pursued as optional commercial systems in the UK, providing additional functionality to those who most desire it. Systems designed to work with the NHS record, such as PAERS, may offer a solution[35]. While this may be economically and practically necessary, it has the potential to further contribute to digital health inequalities.

The problem of system and database interoperability remains a barrier, despite moves within the NHS to introduce consistent technology and data standards, although it is likely that this will diminish with time, particularly as the use of the Universal Patient Identifier becomes ubiquitous.

Access to records alone is unlikely to have a great influence on patient outcomes and the benefits will come to be fully realised only once ePHR become multifunctional, interactive and integrated, supporting optimal patient education and self care as well as optimising remote interactions with the health service. In this way ePHR has the potential to become a truly ‘transformative technology’, defined as *“innovations that fundamentally change care, including self-care, and health delivery in ways that add substantial value to individuals and society”*[36]. To realise this potential, it is essential that the use of ePHR becomes integrated within the processes of care delivery. Achieving this will require efforts not only to develop policies, conventions and incentives for using ePHR but also changed attitudes and expectations amongst clinicians and patients regarding appropriate modes of transaction and the rebalancing of information and status differentials within the new consumer-provider relationship.

The success of ePHR will also be dictated by the involvement of professional and patient consumers at all stages of design, development, implementation and evaluation. This is necessary to generate a sense of ownership, and to ensure that systems meet users' needs and are intuitive and easy to operate.

Internet connectivity is increasingly pervasive across information and communications technologies, thus making the web the logical medium for ePHR delivery in the future. Flexible access through media such as Digital TV, kiosks and web-enabled mobile phone may help to ameliorate the effects of digital health inequalities.

Evidence is needed to inform business models of ePHR, in order to ensure that they are cost-effective, practical and useful to the NHS customer base and to the service, and to accommodate appropriate reward mechanisms.

While further work is required to ground ePHR developments in consumer requirements and attitudes, research needs to move beyond evaluating concepts to demonstrating impacts, if clinicians, health care organisations and patients are to be persuaded to adopt them. The influence of ePHR on cost-effectiveness, safety and clinical and psychosocial outcomes is needed in addition to broader quality indicators such as satisfaction. These efforts may be best invested in the area of chronic disease management in order to demonstrate early benefits, moving towards studies of the broader patient population. Deeper qualitative exploration of the ways in which ePHRs are used by patients with different needs would also be of value for identifying potentially hidden benefits and for informing technology improvements. Importantly, experience with evaluation of health information technology indicates that the outcomes of such research are highly context-dependent, due to a host of socio-technical and economic factors. Thus while research conducted in the USA provides useful indications of a technology's potential acceptability and impact, new research set in the cultural and organisational context of the UK health sector is likely to yield the most useful findings.

Conclusions

ePHR have the potential to impact positively on the delivery of care within the UK, although this will require careful attention to technical, organisational and human barriers, supported by further research to demonstrate objective benefits and contextual influences. We are optimistic about the future of NHS HealthSpace, despite its slow start and the inevitable difficulties that have been faced by the National Programme for IT in England, and supportive of planned records access in other parts of the UK.

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APPENDICES

Appendix 1. Note on ePHR 'rights'

1) Access to the information (more than one might apply)

- a) Personally-entered only
- b) Personally-entered + records of carers, voluntary sector, support groups and charities
- c) Personally-entered + records of health professionals
- d) Personally-entered + records of social services

2) Contribution of information

- a) Private (EPHR is a private space, not shared with or accessed by others except if patient shows others the data)
- b) "Invited" data entry (e.g. patient permitted to enter nominated home monitoring data into a shared EHR space, but nothing else)
- c) Personal health space (patient has autonomy over a dedicated part of a shared record)
- d) Freedom to contribute to all parts of the record (e.g. to contribute or annotate goals in a care plan written by others)
- e) Freedom to correct errors in professional entries etc.

3) Authority over the information

- a) Citizen has a defined and personal access policy created and managed by a professional
- b) Citizen can authorise access by carers and family etc. to his or her EPHR
- c) Citizen can moderate professional access (e.g. hide certain - personal - entries from individuals, teams or roles)
- d) Citizen can fully define or modify authorisation policies for others
- e) Citizen can revoke access by others
- f) Citizen determines all access policies
- g) Citizen controls all exports and links to other systems.

4) Data custodianship (more than one might apply)

- a) Data physically held by citizen (e.g. on their own computer)
- b) Data physically held by provider of the EPHR service
- c) Data physically held by third party with no commercial interest (e.g consumer group)
- d) Data physically held by a single healthcare provider
- e) Data physically held at a regional/national level by the health service or system
- f) Data physically held by an insurer
- g) Data physically held by an employer

5) Interoperability and communication

- a) None (proprietary and closed system e.g. desktop application in the patient's home)
- b) Web-enabled (proprietary system but can be accessed from any location e.g. when on holiday)
- c) Bespoke (proprietary system capable of export but not conforming to a standard - needs a mapping engine to import the data)
- d) Standards-capable (proprietary system capable of export conforming to a standard)
- e) Push-linkable (system has interface to send data directly to other systems, initiated by citizen)
- f) Pull-linkable (system has interface to permit any authorised user or system to retrieve data from the EPHR)
- g) Live-linked (system can both send and receive data from other EHR systems in real time to maintain concurrency)

NB. These themes were helpfully reported and elaborated by participant Dr Dipak Kalra.

Appendix 2. Potential benefits in relation to alternative ePHR models

ePHR that allows patient to see a copy of the clinical record

- may create transparency & foster doctor-patient communication and trust
- may permit the patient to notify the clinician of errors in their record
- may reduce costs of meeting legal obligations to provide copy of record when requested

Patient-held record (e.g. on paper, storage device or internet)

- is more easily accessible to patient and their diverse care providers
- may involve the patient more in their care
- convenient for travel and moving between care providers

Personal web-space for health information (not connected to healthcare system)

- Useful as an aide memoire or for personal health tracking in chronic illness

Integrated & interactive health record (connected to healthcare system)

- Benefits varied but likely to come from interaction and communication through the ePHR e.g.
  - ○ increased convenience and reduced costs to patient of on-line prescription ordering or appointment booking or e-consultation
  - ○ improved medication compliance via integrating reminder messages within ePHR

  - opportunity to integrate ‘hidden’ health behaviours and symptoms
  - linked educational information may promote health and self-care activities

Health-logging ePHR (linked to mobile and wearable technologies)

- Improved or greater self-care through enhanced understanding of symptom patterns and medication effects (using biofeedback and linked education or decision support), and facilitating delivery of interventions as needed, rather than at pre-specified appointment/review times.
- Increased safety via early warning of adverse symptoms
- Reduced need for unscheduled and scheduled care (& reduced cost)

[Synthesis of workshop presentations and discussions]